



Taking a step back: Parents' experiences of the decision-making process for elective orthognathic surgery in cleft lip and palate (IPA)

Jana Safarikova^{a,1,*}, Eliane Young^b, Kiki Mastroyannopoulou^a, Paul Fisher^a

^a Department of Clinical Psychology and Psychological Therapies, University of East Anglia, Norwich Medical School, Norwich, UK

^b Psychological Medicine for Children, Young People and Families, Cambridge University Hospitals NHS Foundation Trust, Cambridge, UK

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ABSTRACT

Objective: This study explored parents' experiences of the transition of responsibility to their child for healthcare decisions relating to their cleft lip and/or palate (CL/P).

Methods: Online semi-structured interviews were conducted with 11 participants (six females and five males, aged 41 to 60 years). They were parents of young people who had decided whether to undergo orthognathic surgery. The data were transcribed and analysed using interpretative phenomenological analysis (IPA).

Results: A responsibility shift from participants to their children was identified in 2 main themes 'A natural process (*or not*)' and 'It has to be their decision'.

Conclusion: The process of shifting responsibility for decision-making to the child comprised a spectrum of experiences from a relief to a shock and upset. Participants went through sometimes difficult negotiating of their ongoing involvement while supporting their child.

Innovation: The importance of addressing psychological aspects of the family system as well as the young person is highlighted here. Addressing the familial complexities of the transition may contribute to the success of the whole process. Clinicians need careful consideration of the potential emotional impact on parents which is not always shared.

1. Introduction

One in 700 babies in the United Kingdom (UK) is born with a cleft lip and/or palate (CL/P), the most common congenital conditions of the face and oral cavity [1,2]. It develops in early pregnancy, the causes for which are complex and a combination of environmental and genetic factors [3]. Despite this, parents often feel guilty and blame themselves for somehow causing their child's CL/P [4,5]. Learning that their child has a CL/P was reported by parents as a shock [6], an emotional and traumatic experience, with parents left feeling overwhelmed with information [7]. While parents are often elated at birth, they also experience a sense of loss, grief and mourning [4,8] and can perceive their children to be more vulnerable compared to those without a cleft [9].

CL/P can impact feeding, breathing, hearing as well as speech, facial development and appearance as well as psychological wellbeing. The UK National Health Service (NHS) offers specialist services with a 20-year care pathway involving several surgeries and interventions from infancy onwards [1-3,10,11] (see Table 1). Parents can experience a

high burden of care and emotional impact as a result [9,12-14].

Whilst many people without a CL/P may undergo orthognathic (jaw) surgery for functional and/or aesthetic reasons [15], studies indicate that for young people with a CL/P around 50 % to 71 % would likely benefit from further orthognathic surgery [16,17]. During surgery, the jaws and chin are realigned and this may help functioning of the jaws and teeth, such as with biting and chewing, and can improve the symmetry of the face. Further surgeries such as lip or nose revision(s) may be considered afterwards as and when indicated. All these surgeries can alter the appearance or profile of the face potentially impacting one's self-image [18,19] and identity [20,21]. This therefore adds complexity to the decision-making for surgery with uncertainty about what the new appearance might be [21].

The lifespan timing of this complex elective surgery means that young people are the ultimate decision-makers, perhaps for the first time, as previously parents held responsibility. A small proportion of young people choose not to undergo this surgery.

The 20-year treatment pathway means that young people do not

* Corresponding author at: Norfolk and Suffolk NHS Foundation Trust, Hospital Road, Bury St Edmunds IP33 3NR, UK.

E-mail address: jana.safarikova@nsft.nhs.uk (J. Safarikova).

¹ Norfolk and Suffolk NHS Foundation Trust, Bury St Edmunds, UK.

Table 1

Treatment timeline.

Intervention	Age of child
Diagnosis of cleft lip at 20-week scan or at birth, antenatal group.	Antenatal care
First MDT* clinic and postnatal group. Specialist advice, newborn hearing screen.	0–3 months
Lip adhesion (if bilateral cleft lip and palate), primary lip repair surgery.	3–6 months
Palate repair surgery	6–12 months
Routine and where needed MDT input*. Surgery to revise palate, or speech (velopharyngeal) surgery if necessary.	18 months–5 years
Orthodontic assessment and treatment, speech and hearing checks, Alveolar Bone Graft (ABG) assessment and surgery if needed. MDT input*.	6–12 years
Orthodontic treatment (usually lasting around 2 years), orthognathic assessment and Palate investigation clinic. Osteotomy (realignment of upper/lower teeth) if needed and opted in (completed after bones finished growing, approx. 18–20 years of age). Other surgeries might be required/requested, eg, rhinoplasty, dental surgery, lip revision, speech surgery, palatal fistulae closure. The treatment pathway typically finishes around the age of 20 years old.	13–20 years
Adults continue treatment or may re-enter the service at a later date if further treatment required.	21+ years

Note: National MDT audits of patients are conducted at 5 years, 10 years and 15 years.

* Multi-disciplinary team input from speech and language therapy, nursing, dentistry, psychology, audiology, paediatrician, surgeon, orthodontist, photography.

usually transition into adult services as they would in other long-term health conditions such as diabetes or cardiology [22]; although this depends in part on each hospital’s specific structure and facilities. In the UK, young people can legally consent to treatment from 16 years of age, or earlier if they are deemed to have capacity and competence [23]. Decision-making for this surgery might represent the significant transitional point for these families. Young people need to consider the risks and benefits of surgery, timing, recovery and uncertain outcome on their appearance and identity [21,24].

Similarly, parents are at a transition point when their children are developing independence and responsibility for their care [25,26]. Although, not a transitional challenge exclusive to CL/P [27], the normative process is made more complex by decision-making around surgery.

Recent studies have highlighted the influence of parents’ and professionals’ values and motivations when supporting young people to make decisions about orthognathic surgery [21,28]. Parents’ views were important to the young people in decision-making, with parents being typically pro surgery.

Routine cleft surgeries were seen by parents as a means to getting closer to ‘normality’; although parents felt simultaneously conflicted by the risks, discomfort and stress associated with them. The complexity

and emotional toil of decision-making perhaps reflected in surgeries being described as a ‘necessary evil’; a sense that choosing surgery was a ‘moral obligation to be ‘good’ parents’’, and an opportunity for their children to achieve their full potential [1,2,24]. It transpired that more support for parents was needed during the treatment journey to address their emotional and social well-being [29].

Parents’ experiences of caring for their child throughout the cleft journey is well documented. The significance of the orthognathic surgery and transition in decision-making has been recognised and researched from young people’s perspectives; however, parents’ experiences are missing [4]. The aim of the current study was to address this gap in research by developing understanding around parents’ experiences in this process. Given that families have access to psychology review at this point in their child’s CL/P treatment pathway, further understanding the complexities of this process would be beneficial for identifying additional and familiar support needs.

2. Methods

2.1. Design

A qualitative methodology explored parents’ experiences of the decision-making regarding orthognathic surgery. Semi-structured interviews were transcribed and analysed using interpretative phenomenological analysis (IPA) [30]. IPA is interested in how individuals relate to the world through the meaning-making process and exploring their ‘lifeworld’ [31], which is in line with person-centred care promoted in the NHS [32].

This study received the required approvals from the University of East Anglia, NHS research ethics committee, Health Research Authority and organisations supporting recruitment.

2.2. Participants and recruitment

Participants represented a purposive sample and were parents of young people born with CL/P who have made a decision about the orthognathic surgery in the last 5 years. If the decision was in favour of the operation, their child still awaited the surgery at the time of this study. This was to avoid the outcome of the surgery impacting on the memory/experience of the decision-making process. Participants were required to have a good understanding and use of English language.

Six females and 5 males took part. Eight of them represented 4 heterosexual married couples. As each participant in these married dyads was considered to have a different experience of the phenomenon in question based on IPA [30], all participants were interviewed individually to gain insight into their personal experience. Participants’ demographics, using pseudonyms, are presented in Table 2.

2.3. Procedure

Participants were recruited through the Cleft Lip and Palate Association (CLAPA) and from a CL/P team in the NHS, following the standard process of gaining consent to contact and informed consent, in accordance with the General Data Protection Regulation [33].

Due to Covid-19 restrictions at the time all interviews were conducted online and lasted between 45 and 90 min. All participants confirmed their consent to take part in the study. Interviews were audio and video recorded. Participants were interviewed alone during a single appointment in a semi-structured manner using a topic guide. All participants were sent an electronic shopping voucher worth £10 after the interview as a ‘thank you’ for their time.

2.4. Analysis

Each interview was transcribed by the researcher into a Word document and analysed before moving to the next one [30]. To ensure

Table 2
Participants' characteristics.

Pseudonym	Gender	Age range	Child's diagnosis	Number of child's prior surgeries	Age range of child when decision made
Emma	Female	46–50	Unilateral CL/P	2	16–17
Peter	Male	51–55	Unilateral CL/P	2	16–17
Joanne	Female	45–49	Unilateral CL/P	5	16–17
Pat	Female	46–50	Bilateral CL/P	4	14–15
Sophie	Female	41–45	Unilateral CL/P	4	16–17
Adam	Male	56–60	Unilateral CL/P	3	14–15
Eve	Female	51–55	Unilateral CL/P	3	14–15
Andrew	Male	51–55	Bilateral CL/P	5-6	16–17
Daniel	Male	56–60	Complete cleft palate	4-5	20–21
Mary	Female	46–50	Complete cleft palate	7-8	16–17
Richard	Male	46–50	Complete cleft palate	7-8	16–17

familiarity with each transcript, the process started with reading and re-reading of the individual accounts followed by making initial notes on the descriptions, use of language and concepts.

Initial exploratory comments and interpretations developed into emergent themes and further into superordinate themes which described the main experiences for that participant [30]. Table 3 offers an example of the analytic process leading to 1 main theme.

Once all transcripts were analysed, patterns across them were sought. Themes present in at least 5 transcripts were selected to form superordinate themes [30]. To ensure the quality and validity of the themes, the transcripts and quotes for each superordinate theme were checked back for evidence. Themes were consulted with the supervisor who also conducted a mini audit from the first transcripts, annotations, codes and themes as well as the structure and evidence of themes across.

Table 3
Example of the analytic process from a transcript to a main theme.

Quote	Coding	Emergent theme	Superordinate theme within transcript	Main theme
<p>“I just think however old your kids get, as a parent... Um, I don't know. It's hard to take that step back. It's just hard, because you- from day one, you know, you have made that decision, it's really, really hard to take that step back, really hard.”</p>	<p>Her role as a mother is changing. She is expected to hand over the responsibility to her child but it doesn't come naturally, it's not a welcome change, it's hard for her to “take that step back”.</p> <p>Stepping back is as if her ‘mother’ identity is lessened?</p>	<p>Stepping back is really hard, not a natural process.</p>	<p>An emotional transition</p>	<p>A natural process (or not).</p>

2.5. Reflexivity

IPA requires researchers to have a reflective stance, to bracket themselves from the participants' experiences [34]. The lead researcher was a female, not a parent herself, with 6 years' experience in health research and/or clinical practice at the time of the interviews. The researcher was not part of the CL/P team but engaged closely with the clinical staff to gain understanding of the cleft pathway and the orthognathic surgery. A reflective journal was kept allowing the researcher to note thoughts and reflections, and supervision took place throughout this piece of research.

3. Results

Two main themes arose from participants' accounts with 2 sub-themes each (Table 4). The themes capture the experience of ‘taking a step back’ and handing over responsibility for decision-making to their child.

3.1. A natural process (or not)

This theme captures the participants' experiences of realising that after years of being responsible for all decisions regarding their children's care participants are expected to hand the responsibility for making a decision about the orthognathic surgery over to their children. All participants shared their experience of stepping back, the impact it made, highlighting a spectrum of experiences and different levels of being comfortable with the change.

3.1.1. A natural process

Four participants experienced the shift of responsibility for the decision to their child as a natural process reflecting the developmental stage of their child as well as what the surgery entails and therefore the need for their child to decide themselves. Participants felt that their children reached an age when they were able to consider implications, pros and cons of having or not having the surgery and make a decision that would be right for them. It reflected that their child was becoming an adult, “we are very proud of him” (Joanne).

As a parent, you feel proud because your child is now taking the ownership for his or her life ahead and deciding this is what I want to do and I'm taking ownership of that decision ... To me it was the right thing to do, let go of the reins, because she has to live with her choice and she has to be happy with the choice.

(Daniel)

Daniel's metaphor “let go of the reins” represented a proud moment for him, seeing his daughter as a mature young woman.

Adam understood the shift as natural but something that was to happen after the operation, not at the time of his daughter making a decision.

Once that big operation is out of the way we can start taking a step back and because she's now an adult and she can take all those decisions for herself, the shift from us to her is slowly happening. I'm sure that after her major- after her jaw surgery the shift is gonna be 75 % her and 25 % us. We shall see.

(Adam)

Table 4
Main themes and subthemes.

Main theme	Subtheme
A natural process (or not)	A natural process An emotional transition
It has to be their decision	I'm not the one going through it Aware of my influence and motives

3.1.2. An emotional transition

Whilst a natural process for some, other participants found themselves experiencing strong emotions during the transition of their role. Three participants found the process of handing over responsibility difficult or surprising. Peter, for example, describes a stunned surprise.

They suddenly hit us with it in a roundabout way. To say, this has to be decision that your daughter has to make. And it's up to your daughter to decide if she wants the op. And I mean, it's her decision only. It's nothing to do with what would anybody else- ... It's just a fact of life. She's growing up. She has to make the decision. There's got to be a time when you let go of the of the purse strings, isn't it? (Peter)

Peter uses a metaphor "they hit us" signifying an unexpected surprise. Yet, on reflection he comes to a new understanding and accepting the shift as "a fact of life", and further normalises the timing of it by another metaphor "let go of the purse strings".

Sophie found it incredibly hard and upsetting that her son was expected to make the decision. In her understanding of being a mother, she felt she should be responsible for all decisions, more notably voice them until her son reached adulthood. This seems greatly embedded in her identity as a mother, that is very important to her, so the news came as a shock.

I remember in my head thinking 'but he's not 18 yet, I should be making that decision' ... The shock of that being announced ... It was like somebody had taken my voice away from me ... It sounds selfish, I just felt that I was no longer needed as mum. Yeah, the only way I can explain it, really.

(Sophie)

In contrast, 2 participants felt a welcome relief when it was suggested to step back. The previous ownership of decisions was laden with worries whether they were making the right decision for their children. They appreciated that the young people had a voice and could decide for themselves.

It sounds really awful, but in a way it was a little bit of a relief. Because as a parent with a child that needs treatment it's all on you. I've got to make this decision. What if I make the wrong one?

(Pat)

In some ways it's a bit of a relief to know that you don't have to make that decision completely on your own, and that your daughter is now old enough to make the decision with you.

(Mary)

3.2. It has to be their decision

This theme captures participants' understanding of the need that their children must decide about the surgery, not them. Nevertheless, the participants continued to play an important role in supporting their children in their decisions.

3.2.1. I'm not the one going through it

Eight participants shared a strong feeling that the decision had to be down to their child due to the procedure itself, the pain and discomfort involved, the recovery time and the unknown impact on their appearance as they were "going into it blind".

She's ultimately the one who has to have the surgery. It's not me that's going through recovery. It's not me who is not gonna be able to eat for two weeks. It's not. It's her.

(Emma)

Andrew felt that if his daughter was aware of the procedure and what it involved, despite perhaps his preference, it was not his place to try and dissuade her. He respected her decision.

When they're describing shaving bits of bone off her hip to insert into her gum, there's always that horrible cold stomach feeling ... So if she can go through that and not worry about it and decide to go a step further, who are we to argue with her?

(Andrew)

Richard also held that it had to be his daughter's decision. He saw himself in an advisory role.

As far as we're concerned, this decision that *she's* gotta make and she's gotta be 100% comfortable with. We would review the facts, go over everything, and then just yeah, and respect, respect the decision she makes. We were just talking to her, helping, supporting, advising.

(Richard)

3.2.2. Aware of my influence and motives

This subtheme was linked with participants' awareness of their influence on their children. Participants reflected on their position and whether they supported the young people objectively, or consciously tried to influence them. Some participants talked about how their worries of pain and potential disadvantages of the surgery might translate in conversations and influence their children. Some participants made a conscious effort not to share their worries with their children.

If I thought about it just as a mum and that's my child, yeah, if you don't have to have it done, don't do it. But that's my view and I was determined that I wasn't going to let her know that that's perhaps how I felt, because that's not fair.

(Pat)

Pat felt it unfair sharing her worries and influencing her daughter. She did not consider it supportive and helpful.

Pain seems to be the overarching theme in Andrew's account. Based on previous operations and seeing his daughter in pain that he could not take away, the idea of the orthognathic surgery seems rather difficult. He uses generalisation to other parents to normalise his concerns about his daughter being in pain, and so did 3 other participants.

[The surgery] sounds like some sort of medieval torture really, doesn't it? ... At the back of my mind is how much it will be hurting. So no, I myself, I wouldn't wish the pain (pressured outbreath) on anybody ... I'm sure most people don't want to see their children in pain, do they?

(Andrew)

Whereas for some participants it was crucial not to influence their child's decision, 2 participants, a married couple, felt that as parents who loved their daughter, knew her and her needs, they also knew what was best for her. However, they were also aware that it was their daughter's decision and she needed time and space to feel comfortable making it.

If she was completely against it because she was too scared, you have to respect it, but my initial things were I'm going to do what I can to put my point across to her because I know it would be for the best ... As parents we see a bigger picture... You have to convince her to try and see, see this bigger picture which as 16-, 17-year-olds or now 18 doesn't always see.

(Peter)

Peter acknowledges the developmental stage of his daughter and the need to support her around the complexity of the decision, to see "the bigger picture". Nevertheless, he is open about his determination to influence her decision-making and "convince her" if he can.

Thinking about decision-making during teenage years, Eve highlighted the influences young people are under.

They're making this decision during a time when they're very influenced by lots of external factors... Socia media, the whole idea of beauty... I'm beginning to wonder whether they make those decisions based on the right reasons.

(Eve)

4. Discussion and conclusion

4.1. Discussion

This study aimed to gain a greater understanding of parents' experiences of their involvement in decision-making about an orthognathic surgery for their child to better support them in the process through increased understanding of the impact on them.

The 2 main themes reflected the changes associated with parents' involvement in the cleft journey in preparation for the orthognathic surgery as their child transitioned into adulthood: 'A natural process (or not)' and 'It has to be their decision'.

Being told about the transition in responsibility for decision-making moving to the young people generated a spectrum of experiences in participants from a relief (eg, Pat) to shock and upset (eg, Sophie). Even if it was a welcome change for the participants, they were facing a complex and emotional situation. They still had their worries and preferences, wanted their child to make the right decision for themselves, while being supportive and respectful of the young person's choice. If the shift came unexpectedly, it took time to adjust to the idea of transition of responsibility for decision making. This adjustment was evident in Peter's and Sophie's reflections on their changing role. The experience of stepping back was influenced by the degree to which participants felt this shift was a natural process (or not). As others addressing transition in long-term conditions found, some parents struggled with not being responsible and accountable for their child's care and had difficulty letting go [35].

Control and protectiveness are characteristics of the parenting dimensions of demandingness and responsiveness [36]. Demandingness is portrayed by the extent of regulating a child's behaviour and/or expecting a child to control their own behaviour, ie, having a varying level of control over the child's actions. Responsiveness represents the extent of fostering individuality in the child, showing warmth, supporting the child's autonomy and being responsive to their communication. This is particularly evident in the second theme where participants let the young person decide about the surgery while providing guidance and support. Whether participants initially felt they wanted to be the ones making the decision or not, they accepted that it had to be a decision made by their child considering what the surgery involved. The extent of demandingness and responsiveness adjusted through the process of transition. However, this highlighted a conflicting experience some participants had, yet not necessarily shared with clinicians and others at the time. It is therefore important that clinicians are aware of the potential internal conflict parents might go through around this surgery and innovate their support and communication through exploring this potential conflict with them. Sharing other parents' emotional experiences, checking their understanding of the process and exploring their expectations of the journey as well as preparing them for the forthcoming changes will allow them time to adjust to the transition.

A key factor in terms of stepping back might have been the age at which the young people decided about the orthognathic pathway. Daniel talked about feeling proud of his daughter making the decision, however, she was one of the oldest, already an adult. Research with young people undergoing the orthognathic surgery identified support with decision-making as a key need [21,28]. This is worth taking into account not only from the young person's perspective but how their age might impact on parents' readiness to step back.

As depicted in the results participants used metaphors to convey

their message and illustrate their experience. Talking about the orthognathic surgery, Andrew likened it to a medieval torture while Peter described his surprise as if being 'hit'. Such metaphors were very emotive, striking, helping the researchers to understand the participants' meaning-making [30] and the impact on participants. While participants experienced these intense thoughts and feelings they reported that they did not express them in front of their children or clinicians, meaning that they were not taken into account during clinical consultations.

4.1.1. Methodological considerations

Due to the COVID-19 restrictions at the time, the study was conducted online using videoconferencing platforms, which is considered an effective alternative to face-to-face research with many advantages [37-39]. Participants were in their own homes, there was no need to travel, which decreased the burden on participants. However, ensuring privacy was crucial as other family members were sometimes present. For example, a participant had to change rooms to continue to speak freely without being overheard when their child arrived home during interview.

A strength of this study was that both mothers and fathers were well represented in the sample (6 and 5 respectively), the latter being underrepresented in cleft research [4]. Parents of children who decided for as well as against the surgery were encouraged to take part. In this study only 1 participant's child decided against the surgery in comparison to 6 young people who were awaiting the procedure. The experiences of this 1 parent contributed to all resulting themes, adding to their breadth.

Nevertheless, 8 participants represented 4 married couples. Although each participant's experience would have been different, it is possible that interviewing one parent per child with CL/P could have enabled more varied experiences to be taken into account.

This was a cross-sectional study capturing one point in time. Longitudinal research starting when the orthognathic pathway is offered until the end of the surgery with both the young people and their parents would offer greater insight into their experiences over time.

4.2. Innovation

This research focused on parental experiences in relation to the changing responsibility to their child for the decision-making process for elective orthognathic surgery. It is important to take a family-systems approach to aid understanding of the complex family dynamics involved in decision-making particularly when young people approach a transitional age for healthcare responsibility. With a view to achieving maximal positive outcomes for the young person, consideration should be given to parental experiences around their altering role. This research suggests to explore parents' expectations of the end stages, including the decision-making processes surrounding the orthognathic pathway, in the years before this point is reached. It is important to highlight that their children are likely to still be underage at the time of preparatory conversations about the decision. Parents can be empowered by the awareness of the process and that their involvement will still be welcomed and required to support their child with the decision. Explaining this to parents earlier on, rather than when presenting the opportunity of the orthognathic pathway, might help shape expectations and prevent negative experiences and reactions towards the final stage.

A further, crucial innovation is for clinicians to support parents in recognising the complexity of the transition in the decision-making, sharing other parents' emotional experiences of the change and being sensitive to the parents' potential internal conflicts around these changes. As the young person is supported to take on responsibility for important decisions, this might be the first sign of altering the existing parent-child relationship as the young person starts to become more independent. Similar discussions dedicated to parents only, in a separate space that allows for honest reflections, could aid parents' wellbeing, serve to better prepare and empower them for their final part of the

orthognathic journey and subsequently support their child better.

This study makes a contribution to evidence regarding transition in decision-making that can be considered across different healthcare services. Keeping in mind what parents might be going through during similar transitions in various healthcare contexts, exploring their expectations and experiences, and supporting them through the process would be beneficial for the parents as well as the young person under care. Nevertheless, it is noted that there may be resource challenges for psychological professionals in providing comprehensive support to the family system in addition to the young person. The potential parental challenges around similar transitions should be shared within the whole MDT whose members of varied professional roles can support addressing them throughout the treatment pathway.

4.3. Conclusion

Exploring parents' experiences of the transition in cleft pathway when they are expected to hand over responsibility for decision-making about an orthognathic surgery to their child brought to light a complex picture. Stepping back after years of holding responsibility for children's health-related decisions represented a spectrum of experiences, from a welcome change and a relief to a shock and upset. Cleft services will benefit from conversations around transition in decision-making from early in the orthognathic pathway and psychologists may have a specific role in more directly addressing airing concerns or issues. Discussing and educating about the transition process early, whilst exploring parents' expectations and experiences of the journey, should empower parents and ultimately benefit the young person. Helping parents to recognise the complexities including the potential emotional impact involved in stepping back, should support parents' wellbeing and in return help them support their child more effectively.

Participant anonymity

We confirm all patient/personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

CRedit authorship contribution statement

Jana Safarikova: Writing – original draft, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Eliane Young:** Writing – review & editing, Resources, Methodology, Conceptualization. **Kiki Mastroyannopoulou:** Supervision, Methodology, Conceptualization. **Paul Fisher:** Writing – review & editing, Validation, Supervision, Methodology.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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